

Outcomes for Disability Services

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Údarás Náisiúnta Míchumais
National Disability Authority

Outcomes for Disability Services

The Department of Health asked the NDA to assist in producing a draft framework for outcomes measurement for the proposed model of person-centred disability services. This builds on and extends previous work the NDA had done in reviewing models of outcome measurement in other jurisdictions.

The NDA has done a background paper, which brings together literature on outcome measurement, examines experiences from other jurisdictions, looks at outcome domains used in different contexts and presents validated measurement tools. This short paper draws on that wider body of work.

An outcomes focus shifts the emphasis to achieving outcomes and not only to undertaking activities and delivering services. Outcome indicators seek to measure the impact of disability services on the lives of people with disabilities. This is different from measurement of inputs (such as number of staff) or measurement of activities (such as number of personal assistance hours delivered).

In disability services, at a national level it is important to know what outcomes people with disabilities are achieving for the considerable public monies invested. Accountability is needed to people with disabilities, their families and the wider public for what is being achieved. As a commissioner and funder of services, the HSE needs to know what outcomes individual services are achieving, as well as across the disability service programme as a whole. Managers of individual disability services need to know what outcomes are being achieved within their service, and how different units of that service are doing benchmarked against each other and against comparable services.

Outcomes framework

The key elements of an outcomes framework are

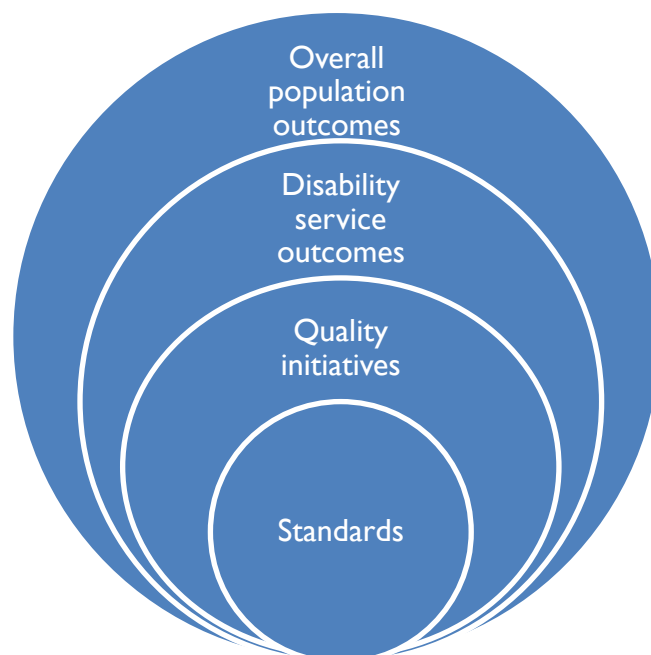
- High level outcome statements or outcome domains
- Sub-domains within those
- Indicators to monitor progress on achieving outcomes
- How measurement is done
 - How often
 - By who – what roles for external measurement, peer measurement and internal measurement
 - How monitoring of outcomes is built into data systems at unit level, service level, HSE level and Department of Health level
- How an outcome-based focus is adopted and embedded into service delivery

Outcomes-based services not a stand-alone project

Re-orienting disability services to an outcomes focus is not a stand-alone project. It nests within a wider focus on assessing how the wider range of government programmes and policies is impacting on the lives of people with disabilities. It forms part of the larger reform programme under way in disability services. It encompasses other activities with an outcomes focus that are designed to raise, measure and monitor quality in disability services including

- Standards – mandatory minimum standards which are independently inspected
- Quality initiatives – where managements take responsibility for a structured approach to continuous improvement, which has an external audit dimension

The diagram below shows how the frameworks for standards, quality systems, disability service outcomes and overall population outcomes are nested within one another



Build on and be compatible with other systems

The outcome domains for disability services should readily map on to domains at other levels of the overall system. This can enable the alignment of the different elements into an overall coherent framework to drive quality and person-centeredness in disability services.

If standards and quality systems are part of a wider outcomes framework, and if high-level outcome domains map on to outcomes being pursued under quality frameworks and HIQA standards, then measurement of achievement of high-level outcomes can draw, in part, on the independent verification of standards, and on the self-assessment and peer-assessment that is an intrinsic element in a quality system.

Consultation

Consultation with service users

The NDA engaged in consultation on its draft set of outcomes with

- People with intellectual disabilities chosen to represent a span of people across different levels of impairment (including people who were non-verbal), different age groups, genders, and living arrangements/type of service. This was done by a specialist contractor, using Easy to Read materials and alternative communication where required
- A mixed group of people with physical and sensory disabilities

Draft outcomes met approval, minor wording change

All the outcomes in the NDA's draft paper were endorsed as appropriate and as important by the individuals who participated in this consultation exercise. It was suggested that the wording of the first outcome statement be amended to remove the reference to 'independent living' as people may choose to live with others rather than alone, or may require support to live in their own home. Some additional suggestions were made in relation to issues that were important to include in the sub-domains.

Supports to achieve outcomes seen as critically important

The only suggested addition to the list of nine outcomes was about support to achieve the outcomes. Consultees emphasised the importance of appropriate supports to enable people achieve the outcomes. These included

- Having the right staff to give good supports
- Being involved in choosing the staff that support you
- Having staff with the right skills and attitudes
- Having staff that know you well and understand you
- Having assistance with communication where that is needed
- Advocacy support
- Access to transport
- Appropriate assistive technology

Comment

The interplay between services and supports, and achievement of outcomes, is extremely important, a point that is emphasised by the literature in this area. However, as supports constitute a mechanism to achieve outcomes, rather than outcomes in themselves, the area of support has not been added as an additional outcome domain. However, in the next stage of the NDA work, which will look at how the outcomes would best be measured, the role of supports will be covered.

High-level outcomes

List of proposed outcome measures

The table below sets out the proposed list of outcome measures, and the sub-domains each would cover. In order to make subsequent tables more manageable, the final column has an abbreviated or summary description of each outcome.

Table 1 Full proposed list of outcome measures

	Outcome	Sub-domains	Abbreviation
	Disability service users:		
1	Are living in their own home in the community	Ordinary housing Suitable housing (e.g. adapted) Choice of who lives with The run of your home Privacy	Living in the community
2	Are exercising choice and control in their everyday lives	Choice Control Everyday routines Major life decisions Positive risk-taking	Choice and control
3	Are participating in social and civic life	Social life Socially connected/not lonely Community activities Civic activities Can access the community (accessibility/transport/mobility) Attends church if so wishes	Social and civic participation
4	Have meaningful personal relationships	Family Friends Intimate relationships	Personal relationships
5	Have opportunities for personal development and fulfilment of aspirations	Education Training Education/training outcomes Realisation of personal goals, both long-term and short-term	Education and personal development
6	Have a job or other valued social roles	Employment Other valued social roles Doing things for others	Employment and valued social roles
7	Are enjoying a good quality of life and well being	Satisfaction with life	Quality of life
8	Are achieving best possible health	Physical health Mental health Healthy lifestyle Preventive care	Health and well-being
9	Are safe, secure and free from abuse	Safety Security and continuity Being respected, listened to Freedom from abuse	Safe and secure

Slightly reworked set of high-level outcomes

The set of high-level outcomes is slightly reworked from the NDA's earlier set of proposed outcomes in order to take on board feedback received during consultation, to better align it with the best practice in outcomes measurement, and to align it to key outcomes in standards for disability services.

The revised suite of high-level outcomes, as shown in Table 2, maps very closely on to other established outcome frameworks from international research and practice, on to the domains used in established quality frameworks for disability services, on to standards for residential and day services, and on to the UN Convention on the Rights of Persons with Disabilities. This mapping exercise informed the changes that were made to the original framework which are:

- To separate the 'social inclusion' outcome into
 - personal relationships
 - wider civic and social inclusion
- To separate the 'participation in employment or education' outcome into
 - Personal development and education
 - Participation in employment or meaningful social roles
- To add another outcome on safety, security and freedom from abuse

Considerations guiding selection of outcomes

Set in a wider model of quality of life and well-being

The overall goal of disability services is to increase the quality of life and well-being of those who avail of such services. The proposed outcome goals and their related core set of outcomes indicators comprise aspects of quality of life and well-being measurement that align with UNCRPD principles; good practice literature; international practice; quality systems; and the wellbeing outcomes as laid out in the National Economic and Social Council (NESC) Report, *Well-Being Matters: a social report from Ireland (2009)*. A section of the NESC report sets out the application of a wellbeing model to the whole population of people with disabilities in Ireland and this model has been used to inform the development of the current proposed outcome framework. The model considered the following aspects of people's lives: economic resources; work and participation; relationships and care; community and environment; health; democracy and values.

Feedback from consultation

Feedback from consultation emphasised the importance of interdependency and personal relationships, and not just independence, for the good life. Other feedback emphasised the importance of appropriate supports, for example personal assistance, to achieving greater choice and control.

Best practice in outcomes measurement

The NDA has reviewed an extensive literature on outcome measurement in disability services. These outcome measures are the output of widespread consultation. There is a very substantial degree of common ground, so the work of Schalock and Verdugo (2002)¹ on quality of life measurement of people with disabilities is used in the table below to represent this literature.

Outcomes measurement in practice

We have also examined systems of outcomes measurement being developed and implemented in other jurisdictions, with Australia being the most advanced. Table 2 shows the outcome measures which have been piloted for Australia's statutory National Disability Insurance Scheme.

Alignment with standards

The NDA has examined the domains relating to service-user outcomes in the draft standards for New Directions (day services) and in the National Standards for Residential Services for People with Disabilities. Both sets of standards were developed through widespread consultation.

Alignment with quality frameworks

The NDA has looked at the domains in different quality frameworks. Those presented in Table 2 below include those from the National Core Indicators (NCI) and the Personal Outcome Measurement System.

¹ Schalock, RL., Verdugo, MA (2002) Handbook on quality of life for human service practitioners. Washington, DC: American Association on Mental Retardation

Table 2 – How NDA outcomes align with other systems

	NDA	Good practice literature (Schalock et al)	International practice 1 (National Core Indicators)	International practice 2 (NDIS Australia)	Quality systems (POMS)	HIQA residential standards	Draft New Directions standards	UNCRPD articles
1	Living in the community	Inclusion	Community inclusion	Home	Live in integrated environments; choose where, with whom they live	2.2 homely setting		Art 19 – living independently
2	Choice and control	Self-determination (personal goals, decisions, choice and control)	Choice/ decision-making	Choice and control	Live the life I want. Choose goals. Choose services. C	1.3 choice and control in daily life 1.6 makes decisions	1.4 right to make decisions; 2.2 meaningfully involved in planning and delivery of services	Principles – Art 3a – autonomy, choice, independence
3	Social and civic participation	Social Inclusion (civic and social participation, supports, roles)	Community inclusion	Social, community, civic	Interact with people in the community. Participate in life of community. Use environment	1.4 personal relationships and links with community	1.6 support to use community facilities & develop relationships in community	Art 19 – community inclusion; Art 29 – voting
4	Personal relationships	Interpersonal relations	Relationships	Relationships	Have friends Have intimate relationships Connected to informal networks	1.4 personal relationships and links with community	1.6 support to develop relationships in the community	Art 23 – home and family

	NDA	Good practice literature (Schalock et al)	International practice 1 (National Core Indicators)	International practice 2 (NDIS Australia)	Quality systems (POMS)	HIQA residential standards	Draft New Directions standards	UNCRPD articles
5	Education and personal development	Personal development (education, training, meaningful activity, assistive technology)		Lifelong learning	Realise personal goals	4.4 education, training and employment opportunities	1.7 progress towards achieving goals, new experiences; 2.4 develop personal and social skills; 2.7 explore own creativity; 2.9 access education	Principle Art 3e – equality of opportunity Art 23 – education Art 26 – habilitation
6	Employment and valued social roles	Material well-being, employment. Personal development – meaningful activity	Work	Daily activity/work	Perform social roles, choose where you work	4.4. education training and employment opportunities	2.6 valued social roles; 2.11 access vocational training and employment	Principle 3c – full and effective participation and inclusion; Art 27 - employment
7	Quality of life	Well-being	Satisfaction	Well-being		2.1 personal plan re quality of life	2.8 health and well-being	
8	Health and well-being	Physical well-being, emotional well-being, access to health	Wellness, medical care, health	Health	Best possible health	4.1 promotion of health. 3.2 support to positive behaviour and emotional well-being	2.8 health and well-being; 3.2 support to positive behaviour and emotional well-being	Art 25 - Health
9	Safe and secure	Rights (advocacy, legal rights, equality, respect, dignity, safety)	Safety, respect		Free from abuse and neglect. Experience continuity and security	3.1 free from abuse or neglect. 3.3 no excess restraint	3.1 protected from abuse	Art 16 – freedom from abuse

Indicators

The choice of indicators under each outcome statement should be designed to

- Validly capture the particular domain
- Focus on key aspects of quality from the perspective of individuals who use services
- Reflect the most important sub-goals or sub-domains
- Validly capture the underlying reality for individuals with disabilities
- Be efficient to collect
- Help services maintain a focus on quality improvement and person-centred services and supports

Valid measures

The NDA has reviewed a number of different suites of quality of life indicators that have been developed in other jurisdictions to monitor outcomes for people with disabilities, such as the US National Core Indicators used in 39 US states. These measures have the advantage of significant consultation and development effort, testing of their validity, and practice in use (See Appendix I). So there can be reasonable confidence that any indicators drawn from such sources will be valid and reliable if used correctly.

The IDS-TILDA study has also developed a number of measures, drawing on a wide literature, to test aspects of quality of life of people with intellectual disabilities. These have been operationalised over two waves of that survey to date.

Perspective of individuals with disabilities

It is essential that the measurement of outcomes includes the perceptions of people with disabilities themselves on what outcomes are being achieved, in addition to any objective measures such as employment rates.

Efficient to collect

The suite of indicators must be efficient to collect. Aligning the indicators as far as possible with information that is already being collected would reduce the task of conducting specific surveys or data collection efforts to track what progress is being achieved on outcomes.

Information being collected for management or quality improvement

Aligning indicators with measures which services are already collecting for management or quality purposes is a good way to ensure that the data is collected, and to align management practice, quality improvement and the overall national focus on outcomes.

A possible risk is that internally-generated information may not be as honest as externally-derived data would be.

Existing survey data

Data that is already being collected via CSO surveys, HRB surveys, or the IDS-Tilda would not require an additional collection effort.

Data from HIQA inspections

HIQA maintain a database of outcomes from inspections of residential disability services. Statistical analysis of this can deliver independent data for services which have been inspected for those outcomes against which they were inspected.

Special data collection

Special data collection for the purposes of monitoring outcomes may be expensive to collect, in particular where it is collected independently by a third part, or through an external peer process. A sampling approach would be the most efficient for such data.

Next Steps

The NDA is examining a wide range of potential indicators. Following detailed study and discussion, the proposal is to conduct an iterative consultation on a set of possibly 30 to 40 indicators to narrow this down to a recommended set. It is proposed to conduct a Delphi consultation with the membership across each of the VfM Working groups and the Steering Group.

Appendix I – Selection of Quality of Life measures

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and efficient	Application & use
Personal Outcome Measures	<p>Developed as part of an accreditation system by the USA Council for Quality and Leadership (based on factors people with disability and their families said were most important to them).</p> <p>Strong client outcome focus</p>	<p>Tool incorporating 21 measures to assess if outcomes and supports are present from the person's point of view; their priorities and preferences are used to identify their personal outcomes.</p>	<p>The 21 Measures are organized around: My Self: Who I am as a result of my unique heredity, life experiences and decisions. My World: Where I work, live, socialize, belong or connect. My Dreams: How I want my life (self and world) to be.</p>	<p>Reported as valid and reliable Involves some subjectivity in decision-making - ratings are based on a number of questions and information collected through various sources May be counter indicated for individual QoL monitoring because of lack of sensitivity within some domains and no subjective QoL component despite domains being similar</p>	<p>Outcomes either met/not met – resulting in limited sensitivity. Scoring considers personal relevance of outcomes by considering whether outcomes that are not present are based on personal choice</p>	<p>Can be personnel intensive Used in USA as part of accreditation process with individuals meeting with CQL staff member for a personal outcomes interview.</p> <p>Follow up is done by others who know the person best</p> <p>Documentation checks are used to further evaluate the presence of outcomes for each person</p>	<p>Intended to be used as part of an accreditation process. Copies of Personal Outcome measure material available</p> <p>1-9 sets, \$149; 10-19 sets, \$139; 20 or more sets, \$129</p> <p>Training is required to understand use tool.</p> <p>Cost can be a barrier to wide spread use.</p>	<p>Can be used as a guide for person centred planning, service re-orientation and for quality/accreditation.</p> <p>Used with people with disability including those with a range of intellectual and developmental disabilities and mental illness.</p> <p>The CQL database allows benchmarking of results against over 5500 interviews.</p> <p>Includes a measure of social capital</p>
National Core Indicators	<p>Under development since 1997, to formally measure the performance of disability service providers in the USA.</p>	<p>NCI supports member agencies to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare results across states, and to establish national benchmarks</p>	<p>Five key indicators: Individual outcomes; Health welfare and rights; System performance; Staff stability; Family indicators</p>	<p>Data is widely used to inform policy, develop QA systems and compare performance with national averages. Also used as basis for data briefs in particular disability policy areas.</p>	<p>Extensive evidence of indicators ability to measure changes in individual circumstances</p>	<p>Intrinsic data collection requirements mean effort is needed to enter returns.</p>		<p>29 States in the US are participants in the Project.</p>

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and efficient	Application & use
University of Toronto Quality of Life Profile (QLP)	Began development in 1991 for the Ontario Ministry of Community and Social Services to assess QOL among persons with developmental disabilities	Seen as being applicable to all persons, with and without disability Developed through analysis of literature and data from persons with and without disability. Includes a holistic view of quality of life. The person's perspective of their quality of life is formed by considering the relative importance attached to each particular dimension and the extent of the person's enjoyment of that domain.	Being, Belonging, and Becoming and their sub-domains are determined by two factors: importance and enjoyment.	Reported as psychometrically sound. A publication about the tool's psychometric properties is being prepared. There are reliability issues due to assessor judgement.	Identified by a Report on Quality of Life Instruments commissioned by DHS Victoria as having the best conceptual basis and range of domains to cover client aspirations and most disability service interventions	Instruments can be used for interviews or self administered A multi method, multisource approach is used to gather information that involves interviews, checklists, observations and data provided by the person with disability, service provider and independent assessor.	The cost of both the long and short physical and sensory disabilities version is \$35 Developmental Disabilities tool (includes 3 different instruments and a manual for conducting the assessments) \$75. Permission to make up to 99 copies: \$50.00 Permission to make 100 plus copies: \$75.00	Suitable for people aged 18 to 64 years. Specific versions exist for: physical and sensory disabilities developmental disabilities adolescents adults seniors. Uses include: service improvement individual person centred planning and outcome monitoring. Concepts are not always represented briefly, simply or clearly.
Schallock & Keith The Quality of Life Questionnaire (QOL-Q)	Developed after 12 years of research It aims to help evaluate existing programs and to devise new ones	40 items scale with 4 subscales each of 10 questions Complex questions and response categories (involves comparison to the average person).	The domains are: Empowerment/ independence Competence/ Productivity Satisfaction/ Social belonging/ community integration. The tool is more narrowly focused than some other measures	Extensively studied and used in research Adequate internal consistency; test-retest and inter-observer reliability; discriminant validity); and validity of scale (content, construct and discriminant validity).	Sensitivity demonstrated with higher scores from people living independently than in supported accommodation and people who are employed than those unemployed	Administered by trained interviewer reading each question aloud and respondent pointing to a 3point Likert scale response. Administration Time: 20 mins	\$50.00 US	Designed for Ages: 18 and above. There is a form for school aged adolescents. Most widely employed scale for QOL measurement for people with intellectual disability. Nebraska USA has used it also for developmental disability service provider profiles. Not suitable for people with severe levels of intellectual disability that cannot respond for themselves. The instrument claims it is well suited for person-centred planning, quality-oriented service provision, and service evaluation.

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and efficient	Application & use
Ask Me! Quality of Life Questionnaire	Used as a basis for the evaluation, reporting and quality improvement of QoL in US Maryland Agency data also used to develop state-wide provider profiles	A survey of 56 items to study the quality of life of adults with developmental disabilities	The domains are: Social inclusion; Self determination; personal development; Rights; Inter-personal relations; Emotional wellbeing; Physical wellbeing; Material wellbeing; Transportation availability	Extensive reliability data	Reported to demonstrate variation in measurements: and statistical significant increases in domains: among community agencies and when QA plans are developed by agencies	Face-to-face interviews conducted by trained peer interviewers who have developmental disabilities.	The Ask Me! Survey is copyrighted. It is available at cost and includes the survey, interview protocol, and interviewer training information. The Arc of Maryland has a licensing agreement for entities wanting to become certified to use the survey	Appears mainly to be used in Maryland USA. Used for policy, quality improvement and progressing service delivery toward self- determination and rights. Scoring has been developed for use for people who are non-communicative (using happy/neutral/ sad face). Tool includes pre-interview questions. If the person is unable to communicate two proxies are used.
6. Personal Wellbeing Index	Refinement of the Comprehensive Quality of Life Scale (ComQoL) (Cummins) that was developed at Deakin University for Australian population.	Based on the well-established ComQoL. The ComQoL is still available as the pre-testing protocol to establish respondents' competence at the task and the use of cartoon figures and faces to elicit responses are useful and can be applied to the Personal Wellbeing Index. Results of surveys of the Australian population are available	8 domains are used in the adult scale: standard of living; health; life achievement; personal relationships; personal safety; community-connectedness; future security; spirituality-religion	Reported to be reliable and valid Psychometric for the Comprehensive Quality of Life Scale (ComQoL) were well established with norms of people with and without disability established The Personal Wellbeing Index needs to be trialled to establish its psychometric performance with school -aged children, and people with an intellectual or cognitive disability	Appears to lack sensitivity to service provider's intervention D'eath et al report the instrument while reasonably accurate for groups may not be as accurate at the individual level Significant differences between elderly people living in different accommodation and parents with/ without child with intellectual disability but may lack sensitivity to life changes associated with service intervention	Administration takes from 10 to 20 minutes but may take longer for people with intellectual disability or cognitive impairment.	Able to be downloaded free of charge	The PWI scale can be used with any section of the population - allows benchmarking to whole population norms Versions of the tool developed for people with intellectual/ cognitive disability. Incorporates a pre- testing protocol to determine whether, and to what level of complexity, respondents are able to use the scale. Uses 0 to 10 Likert scale; includes alternate response formats e.g. 2, 3 or 5 blocks or faces. Proxies not to be used. Difficulties in use with people with communication difficulties

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and efficient	Application & use
Goal Attainment Scale (GAS)	Developed in the 1960s as a tool for monitoring and evaluation in human services	A method for setting goals and measuring the degree of goal achievement by creating an individualised five point scale of potential outcomes undertaken for an activity	Specific domains (goals) can be identified depending on the project.	<p>Testing has demonstrated that GAS is: Easy to use; Provides a clear measure of goals achieved;</p> <p>Goal achievement is quantifiable Scores, for multiple goals, can be amalgamated into one overall summary score demonstrating the degree of achievement of a project.</p>	One challenge with GAS is skilful setting of goals so that goals are neither too easily attained, thereby inviting over- achievement, or alternatively, set so high that goals cannot be achieved	<p>The versatility of GAS is such that it can incorporate goals of all types.</p> <p>The emphasis has to be on the logic of the structure designed. For example, goals can be hierarchical, where achievement of one goal allows another to be embarked on</p>	Templates are freely available in excel format	Can be used across a wide range of projects, programs and applications
Outcomes Star	Developed in 2003 to measure outcomes across a series of programs and service delivery types	Measured outcomes across a series of scales, later grouped into a star graphic. Support as well as measure a process of individual change	<p>Measured outcomes across a series of scales, later grouped into a star graphic.</p> <p>Support as well as measure a process of individual change</p>	Multi service/project applicability with different domains per project. They include (e.g. Autism Spectrum Star): Physical health Living skills & self care Well-being & self-esteem esteem Sensory differences Communication Social skills Relationships Socially responsible behaviour Time and activities	All versions are based on an explicit model of the steps that service users take on their journey to independence – “The ladder of change”	The process is highly interactive, with collection and analysis of data including active input from service users and workers the fundamental aspect of the model	May be used in print format free of charge, licenses are available for online or commercial.	<p>Fourteen versions of the star have been developed including for Autism Spectrum and learning disability</p> <p>A vision impairment star is under development.</p>